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ABSTRACT

The presence of HIV-positive children in preschool and day care programs is becoming more widespread as medical research discovers new drugs to combat the disease. This paper examines one child's experience in his first 3 years of school in the Bronx, New York. The paper begins with a description of how teachers are becoming more aware of children with HIV in their programs as parents' concerns about their child's school experience take precedence over privacy concerns, and as parents need an understanding person to confide in regarding their child's condition. Statistics on the number of pediatric AIDS cases in the Bronx are presented. The paper maintains that preschool educators must be prepared for the inclusion of HIV-positive children because these children have the legal right to attend. The experiences of Darren, a child who contracted HIV perinatally, are presented. The focus of the presentation is on his mother's efforts to collaborate with administration and teachers to ensure quality care for her son, her openness about her son's illness and her own lifestyle, his adjustment to preschool, his development and knowledge about his illness, and his preschool and kindergarten experiences. The paper includes recommendations for teachers regarding preschool activities and handling first aid situations. The report concludes that teachers need to receive accurate information about HIV and AIDS and that when teachers become comfortable about having a child with HIV in their class, they can proceed in a normal fashion. (Contains 9 references.) (KB)

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MANAGING PRESCHOOL WITH HIV: A TEACHER'S EXPERIENCE WITH A FAMILY IN CRISIS

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Abstract

The presence of HIV positive children in preschool and daycare programs is becoming more widespread, as medical researchers discover new drugs to combat the disease. Children are living longer with HIV, and their attendance in schools is inevitable. Administrators and teachers are learning more about HIV and are accepting the fact that preschool is good for the child with HIV, as it is for unaffected children. What is life like for the child who has HIV and attends a preschool program? One child's experience in a Bronx day care center is examined.

MANAGING PRESCHOOL WITH HIV: A TEACHER'S EXPERIENCE WITH A FAMILY IN CRISIS

INTRODUCTION

The word is out. Children with HIV are present and performing capably in the preschool classroom. How are teachers, parents, and administrators coping?

Teachers in day care were once unaware of the fact that children with HIV were existing in their programs. The once upon a time privacy rule no longer takes precedence over a parent's concern about their child's school experience. Some parents are no longer ashamed to inform their child's teacher about the child having the HIV virus. Parents need an outlet and an understanding person to confide in and trust. Most of the time, their child's teacher fits this profile. Expressing their plight is a way for them to form a partnership with their child's caregiver; working together for the good of the child.

Mrs. Paul has to pick up Darren early today because he has a visit with his doctor. I ask his mother, "Does he have a cold?" Teachers usually want to know about the health of their students. Mrs. Paul confides, "He has HIV and I have to take him for a cell check."

As of September, 1997, the New York City Department of Health reported 1,813 known Pediatric AIDS cases. Reported cases for Bronx Pediatric residents total 501, 50 additional cases for non-residents who were hospitalized in the Bronx are excluded. The Pediatric community consists of children aged 12 and under (New York City Department of Health, 1998, p. 16).

Children infected with HIV are living longer and thriving due to promising drugs that are used to treat the disease (Foley and Kittleson, 1993, p. 342). The likelihood of a teacher having to instruct a child with HIV is increased due to this phenomenon. Preschool educators must prepare for the inclusion of HIV positive children in their classrooms. Children with AIDS are granted the right by law to attend preschool and group day care (Foley and Kittleson, 1993, p. 342). Administrators and staff personnel should receive accurate information and training, to develop skills and knowledge to meet the needs of infected children. Many children will need special assistance that requries collaboration among educators, health and social services (Cohen, Papola, and Alvarez, 1994, p. 13). It is absolutely necessary for caregivers to work together to provide a safe, nurturing environment for

children infected with the AIDS virus.

DARREN'S STORY

The summer of 1995 had barely begun to scorch the borough of the Bronx, when a bright eyed, frisky little boy, was delivered weighing five pounds, 3 ounces. Darren had contracted HIV perinatally. The New York City Department of Health reports that 96 percent of Pediatric AIDS cases resulted from maternal transmission (NYC Dept. of Health, 1998, p. 7). Darren has survived the incubation period, and is experiencing life as a preschooler in day care. Darren's admission into the day care program brought relief and excitement to his mother. She was pleased to learn that Darren could not be refused enrollment into a publicly funded program because of his illness. Darren's mother, whom I will refer to hereafter as Mrs. P., is extremely concerned about his well being. Darren is under the constant care of health care providers. "Regardless of the stage of infection they are displaying, children with HIV will require ongoing medical care" (Bruder, 1995, p. 84). Mrs. P. has made every effort to collaborate with administration and teachers to ensure quality care for her son. She has decided

to be open about his condition.

Because there is a stigma attached to AIDS many people are reluctant to divulge their association with the disease. Mrs. P., being well aware that some people are living longer with HIV, is not afraid to speak out. Others are fearful to admit that they are infected or whether a family member has contracted the disease. Mrs. P. volunteers information about Darren's status, and has instructed his physician to provide information regarding his infection. The school nurse reviews Darren's health records every six months, and answers any questions that his teachers may have. Day care personnel has been informed to adopt universal precautions in order to reduce their risk of infection with HIV. Universal precautions are accepted practices used to prevent the spread of any infection or germ. Paasche and colleagues (1990) prepared a resource book that includes the necessary precautions that schools should take when they admit children with HIV, entitled **Children with Special Needs in Early Childhood Settings.**

Mrs. P. speaks freely about her own life as well. She is an admitted former intravenous drug user. Cohen's (1994) study found that one-half of the in-

stances where children are infected with HIV, the mother contracted the disease from an intravenous encounter with an infected needle. Mrs. P. contracted the virus over 10 years ago. She has had repeated hospitalizations and receives ongoing medical care. She expresses sadness when she talks about the welfare of Darren and his brother, who is one year older, and also infected with HIV. He is presently not exhibiting any symtoms. "Children who are infected with HIV vary widely in the severity and manisfestation of their infection" (Bruder, 1995, p. 84). Mrs. P. is frightened about leaving her children in this world without a mother.

Kozol (1995) makes references to the fact that large numbers of children are orphaned or being raised by fathers because of the AIDS epidemic. Mrs. P. does not believe that the children's father is capable of caring for them alone. He depends upon her for direction in their lives. Mrs. P. has been fortunate, she has remained healthy and capable of attending to her family. Darren's daily care rests solely on his mother's ability to supervise what happens in his life. The health of mothers who are infected with HIV dictates their involvement with their children's ongoing

care (Bruder, 1995, p. 88). In spite of pessimism about her own fate, Mrs. P. manages to obtain hope that Darren will have a future. She has every reason to be hopeful, HIV is slowly becoming a chronic but manageable condition (Cowley, 1996, p. 62).

THE PRESCHOOL EXPERIENCE

Preschool has been designed to prepare young children for a smooth transition into the primary grades. Preschool educators are employed to provide quality care to children from diverse backgrounds, the preschooler with HIV are to be addressed as the child's teachers plan their curriculum. Provisions should be made for the child's inclusion in natural activities. Every effort should be made to increase the child's individual participation and enjoyment (Bruder, 1995, p. 94).

Teachers ought to realize that children with HIV pose little threat to other children, so that group activities involve little or no risk. We know that most preschoolers enjoy free play, and boys especially engage in rough and tumble play. Children who have HIV should not be excluded from these forms of activities. Teachers do not have to be concerned about

minor injuries. Teachers are often required to administer first aid for minor playground injuries. The correct procedure for handling bleeding wounds of children with HIV, is the same for all children. A study instituted by Foley (1993) indicates that teachers become comfortable in the delivery of care to students with HIV, once they have received proper and informative knowledge about HIV transmission. In school settings, children with HIV are to receive normal treatment as much as possible. Therefore, it is essential for school staff to be given preservice and inservice training.

Darren's experience in preschool began when he appeared at the doorway of classroom 3A, holding his mother's hand, pulling back as he screamed "no." Imagine his anxiety. This is a child who has been to clinics, facing health care providers more times than most children have by age three. He does not have any idea that this is a place where he will do the exploring, expanding upon his interests, developing knowlede about himself and the world around him; not a place where he will be poked with a needle so that his blood count can be examined. Reluctantly, he allows Mrs. P. to guide him into the classroom. After a few minutes

of his mother and myself offering reassurance that school will be enjoyable, Darren settles down. He sits in circle, wide-eyed and observant.

As each day passes, Darren becomes better adjusted to his new environment. He is not extremely verbal, and displays a moody demeanor. He smiles and plays with the children in class nicely, and suddenly he becomes somber and goes off to play alone. There are instances when he would rather not focus on any one activity. He would prefer to aggressively disturb his peers, and defiantly disobey his teachers.

Six months into the threes, Darren improves in the areas of cognitive development, but continues to have difficulty in his social and emotional behavior. Cohen (1994) indicates that a high percentage in the frequency of neurodevelopmental dysfunction exists in children with HIV. Deficits in social and behavioral areas are included in the list of abnormalities associated with neurodevelopmental dysfunction. Darren's abnormal behavior could be linked to neurodevelopmental problems, but there are other issues that may have an adverse impact on his development. His mother's substance abuse experience, and biological condition during pregnancy may contribute to Darren's situation.

DARREN'S WORLD: WHAT HAVE WE LEARNED

Darren and his parents are sitting in a waiting room at the clinic. There are several children who are also infected with HIV. He points to a little girl who is extremely thin, and suffering with a severe case of thrush (a fungus infection in the mouth) which can be seen as she opens her mouth. He asks his mother "what's wrong with her mouth?" Mrs. P. looks over at the little girl who appears to be the same age as Darren, and explains that the little girl is sick, and has HIV. She lets Darren know that the little girl is not doing as well as he, but the doctors are going to help her. Darren is living with the burden of HIV, yet he remains inquisitive about everything around him. He wants to know if he will "get the white stuff in his mouth," and feeds his other curiosities as he waits to be seen by the doctor. Mrs. P. explains Darren's illness to him as clearly as she can. She lets him know that she loves him and brings him to the clinic because she wants him to be well. She gives him plenty of encouragement and care.

It is important for parents and caregivers to be as honest and explicit as they possibly can, to the children in their care. Children need to receive ac-

curate information about the disease, and learn how to properly care for themselves. Parents, teachers and other caregivers should always communicate information to children in a developmentally appropriate manner.

Mrs. P. asks Darren's teachers to inform her about any illness that other children in his class may have. She is especially concerned about serious illnesses, such as chicken pox or measles. She explains that Darren can become seriously ill if he is exposed to infections of this sort, because his disease fighting system is weakened by HIV. Darren's teachers are grateful to Mrs. P. for sharing information about Darren's condition. Her openness will help them to understand issues facing other children who are infected with HIV.

Darren is usually enthusiastic about beginning his school day. His teachers observe his deameanor when he enters the classroom. They are concerned about his mood. There are days when he is not the perky little boy they have come to know. When Darren is melancholy his teachers understand that he is not up to joining the class for scheduled activities. He is allowed to chose an activity that suits his mood; or rest if he choses.

Darren's kindergarten class is preparing for graduation. This calls for special attention and extra work from the children. One day as the class is given instruction on how to perform a dance for the eventful day, Darren becomes extremely serious. He watches as his teacher points out each dance move, and follows along attentively. She looks over at him and compliments him on his achievement, as he correctly manipulates his body. She is happy to express to me later, that she was astonished to see that Darren was anxious to pick up the dance steps. He is usually interested in "doing his own thing." He was working very hard to accomplish the goal. His determination continues to excite his teachers. Darren is independent and assertive, in spite of having to receive special care and monitoring. Perhaps the excitement of going to another school is making him feel like a big boy, and he is responding accordingly, or he is maturing; developing a sense of self control.

Darren's teachers observe him at play with his friends, and watch as he learns new things. They believe that this is a world of normalcy for him. They also believe that he experiences a world of uncertainty everytime he visits the clinic. Can he be sure

that the same children who were there when he last visited, will be there on his next visit? I wonder if he has feelings about this, ones that he can not express. I also wonder if he has any feelings about discovering the same friends at school each day. I reveal my thoughts to Mrs. P. when I see her, she says that Darren notices the children when he is at the clinic, and does not comment when one no longer shows up.

Darren has adjusted positively to his life as a preschooler. He understands that he will attend elementary school with his brother. Each one of his teachers, former and present, hope that his new life brings him continued health and pleasant discoveries. The rite of passage to his new school brings sadness and joy to all of us. We have to sort out conflicting feelings of lament and delight. We must embrace only the pleasure of knowing that Darren is on his way to yet another educational journey.

Conclusion

As Mrs. P. shared her family situation with all of Darren's teachers, daily contact with him became easier. The information that she brought to us about

HIV and AIDS was welcomed. Studies have shown that teachers need to receive accurate information about the AIDS virus and how it is transmitted, so that they can provide proper care to children with the disease (Foley and kittleson, 1993; Cohen, Papola, and Alvarez, 1994; Bruder, 1995). Darren's four year old group teacher expressed concern that she had not learned enough about HIV while he was in her class. She was pleased to speak with me and discover new insights to use with future students.

Once teachers became comfortable with the idea of having a child with HIV in their class, they were able to go about their day in a normal fashion. They were not panicky about attending to minor injuries or engaging in preventative measures to prevent the spread of germs that can cause disease. Mrs. P. helped to alleviate any concerns that Darren's teachers expressed, and the school nurse helped to assure a positive experience for everyone.

When Darren's teachers realized that he would be leaving the school for good, the fear of not seeing him daily became real to them. The three years that Darren spent in our school was coming to a close. I began to think to myself that the subject of death

never came up during my discussions with Darren's teachers. I began to realize that we saw Darren as a vital part of our school and not a diminishing presence. It has also occurred to me that the issue of death and dying are not usually thought of when children are the subject of conversation. Cohen (1994) suggests that staff must be prepared to deal with the issue of death and dying because a cure for HIV has not been found.

Darren's teachers express empathy for a boy who has to endure discomfort, and admiration for a boy who finds the strength to manage school. The nourishment and care that Darren receives from his family is evident each and every time he walks into the school building. He is fortunate to have everything that he needs in order to develop to his fullest potential.

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